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"It's scary, scary, scary...": the lived experience of asthma

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UNIVERSITY OF
LINCOLN



(1)

Research programme – 3 projects on lived experience of asthma in non-élite sportspeople – sociological phenomenology

- 3-year research study including PhD project – Dr Helen Owton, at Exeter (now Open University)
- 3-year autoethnographic & autophenomenographic study of women's distance running
- 1-year Research Infrastructure Funded project at Lincoln (HART colleagues, Helen Owton, Niro Siriwardena) – data analysis ongoing

Today specific focus on two dimensions:

- Asthma as 'dys-ease' (Leder, 1990) – lack of control
- Bodily attunement & learning control



JAC

Asthma

- Breathing *disorder*, inflammation of airways deleteriously affects pulmonary ventilation; myriad symptoms e.g. coughing, wheezing, breathlessness
- >5 million people with asthma in UK, attacks result in hospitalisation of sufferer every 7 minutes (Asthma UK website, 2013)
- c. 3 people per day die from an asthma attack (Asthma UK website, 2015)
- Exercise-induced bronchoconstriction (EIB) found in c. 80-90% of asthmatics – exercise & physical activity therefore as problematic
- Moderate/intense physical activity tends to provoke bronchoconstriction
- But regular physical activity - physical & psychosocial benefits
- Distinct dearth of qualitative research on lived experience of asthma amongst sports participants & committed exercisers



(3)

Table 1: Participants in the interview-based study

Participant identifier	Age	Gender	Current/previous competitive/semi-competitive status	Current/previous competitive status	Researcher
Participant 1	32	Female	Former competitive (Asthma UK)	None	Identified
Participant 2	35	Female	Former competitive (Asthma UK)	None	Identified
Participant 3	38	Female	Former competitive (Asthma UK)	None	Identified
Participant 4	40	Female	Former competitive (Asthma UK)	None	Identified
Participant 5	42	Female	Former competitive (Asthma UK)	None	Identified
Participant 6	45	Female	Former competitive (Asthma UK)	None	Identified
Participant 7	48	Female	Former competitive (Asthma UK)	None	Identified
Participant 8	50	Female	Former competitive (Asthma UK)	None	Identified
Participant 9	52	Female	Former competitive (Asthma UK)	None	Identified
Participant 10	55	Female	Former competitive (Asthma UK)	None	Identified
Participant 11	58	Female	Former competitive (Asthma UK)	None	Identified
Participant 12	60	Female	Former competitive (Asthma UK)	None	Identified
Participant 13	62	Female	Former competitive (Asthma UK)	None	Identified
Participant 14	65	Female	Former competitive (Asthma UK)	None	Identified
Participant 15	68	Female	Former competitive (Asthma UK)	None	Identified
Participant 16	70	Female	Former competitive (Asthma UK)	None	Identified
Participant 17	72	Female	Former competitive (Asthma UK)	None	Identified
Participant 18	75	Female	Former competitive (Asthma UK)	None	Identified
Participant 19	78	Female	Former competitive (Asthma UK)	None	Identified
Participant 20	80	Female	Former competitive (Asthma UK)	None	Identified

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(4)

1) Asthma as generative of 'dys-ease'



- Leder (1990): in 'normal', healthy state, mundane, taken-for-granted experience of the body marked by 'ease' - lack of self-reflection & self-awareness
- Body as 'backgrounded', 'absent'; not focus of intentionality; thus '**disappears**'
- When everyday bodily routines interrupted - e.g. illness, pain, injury, intense sensation
- Body breaks into consciousness; thus '**dys-appears**'
- So, asthma body dys-appears when breathing becomes difficult - self-conscious awareness of being a body in the world

(5)

- For those suffering more severe asthma attacks, unpredictability & onslaught of asthma upon the body generated feelings of panic, Heideggerian (2005) 'thrownness', of being 'caught out' by one's own body, reliant upon inhaler:

It just feels like I can't, I can't get the air in... and that's the main uncomfortableness of it. But then it's like the panic side of things as well, is that I'm not getting the air in at the moment. I can't sort of get enough air [laughs] to make me feel good. You know when you feel satisfied and you have a deep breath, I can't sort of get that... and that's what makes me feel uncomfortable and then it's obviously like, oh god, I'm not breathing. This isn't working, that yeah that, mainly physiological but it's also shit, panic, the panic side. (Lucy, 20s, swimmer)



... panicky [...] not very nice... your chest just doesn't get, bring in the air in... so... um... it's a bit scary... but then you take your blue inhaler and it's alright. (Jane, 80s, former ballet dancer)

(6)



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(7)

- Male participant evocatively described the 'black zone', when an asthma episode would develop into a severe, life-threatening attack:

• ...you can't breathe either way in or out, for some time, I think that's black... They do say if you drown you get this sense of beautiful calm and I did not get that. It was... vigorous. Choked, glorifying panic of... I have to find a way to get air into my lungs... It was very, very scary. It was more scary than dangling off a cliff or, you know, being in a car accident or anything that's like, oh this is it then. It's scary, scary, scary thing and it's immediate, and there's no time for your life to flash before you, you just think, how the f**k am I going to breathe? (Ivor, 40s, golf player and climber)

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(8)

Frightening for others

- *On a personal basis, I mentioned a minute ago I didn't realise my daughter had exercise induced asthma until she was running in a school race. And she was coming round the corner of the field in her little running race, her lips were blue and I thought, and she was really struggling to breath.*
- *So although we suspected then she might be borderline asthmatic seeing her like that, and that was strictly exercise induced, it's quite frightening to see actually. (Nurse practitioner)*

JAC

(9)

2) Bodily attunement: breathing 'work'

- Sociological & anthropological literature on sensorium - ethnographies of sound, the soundscape, 'acoustic knowing'
- 'Deep listening': careful, analytic auditory attention; attunement to nuanced & multiple layers of meaning enfolded in sound (Allen-Collinson & Owton, 2014)
- For asthmatics - noisy, heavy breathing, wheezing, coughing, spluttering = highly salient 'non-symbolic sonorous expressions' (Vannini et al., 2010: 331)
- People with asthma perennially 'listen' to their bodies, anticipating & monitoring symptoms
- Sportspeople & exercisers - often become acutely aware of, and attuned to their & others' breathing patterns through their training (Hockey & Allen-Collinson, 2007)
- Motivated to manage their asthma & control the body

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(10)

- Highly refined auditory work & careful monitoring of sound AND proprioceptive indicators (e.g. feelings emanating from lungs, bronchi & trachea) evident in the data
- Fine corporeal attunement to tiny nuanced changes in the body & body-world relationship:

• *When I'm doing sport ... you're constantly aware of you know, the way you're breathing and the air ... your mouth and nose covered in cling film or like a carrier bag, and you've got a few tiny pin pricks in it to let the air in. (Eve, 20s, football, cycling, swimming)*

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(11)

• *I can by now detect the exact moment that signals when my breathing will tip into wheezing and asthma – or rather to be more precise, the exact exhalation. There is something about the quality of that outward breath that alerts me to an imminent bout, a tightening of throat and upper thorax, a tight squeak on exhalation, and I know at that point I have to act... It's difficult to describe exactly, but I've learnt how to steady my breath, to drop the pace, just fractionally, to think calm...reduce the friction in my intake of breath and relax the small depressed area between my clavicles.*

- (Autophenomenography, February 2008)

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(12)

Somatic learning & control



- With benefit of lived experience & developed attunement to body's reactions to EIB, some participants learned to expect & predict (to some extent) somatic reactions, engendering feelings of being more in control:
- *I'd start the run and within 5 minutes, I'd notice that my breathing's a bit restricted, but after about half an hour and 25 minutes, it goes away...* (Betty, 30s, marathon runner)
- *I can think of [when] asthma was a real nightmare. Loads of times, when I've been running with X, and going whoa, I'm really wheezing here at the end... I'd be going [heavy wheezing noises] and waiting for it to calm down, but knowing that that's what you do... we're both struggling hard, trying to beat each other ... lungs burst, legs burstin', everything's burstin'...* (Nick, 30s, runner, martial artist)

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Patient & practitioner co-working

- They are really motivated the ones I have come across, they manage themselves so well because they are dedicated to training they know their bodies, they listen to their bodies so they are the best managed ones. (Nurse practitioner)
- I think that's where your treatment plan comes in, because if you can devise your treatment plan with your patient you have got them on board, they are fully aware then what to do and when to do it. You are giving them the control with the right information and education to go and be independent which is what we are trying to promote. And a normal lifestyle. (Nurse practitioner)

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Why sociological phenomenology?

- ✓ Extends/challenges conceptualisation of 'object body' (*Körper*) of much biomedical science – acknowledges 'subject body', the lived body (*Leib*)
- ✓ Important for healthcare professionals, coaches, *et al.* involved in support of athletes/sportspeople to listen to, respect, seek to understand the 'insider' perspective
- ✓ Sportspeople have often developed high degree of attunement to somatic signals
- ✓ Treatment plan as co-production between patient and healthcare professional
- ✓ Implications for better, tailored treatment modalities & programmes – potential for enhanced adherence over longer time-frame

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